# HAEMATOLOGY PATIENT DIARY

A guide for patients, families & whānau



Vision to Cure. Mission to Care.

#### INTRODUCTION

This diary has been created to help you and your family/whānau to keep a record of your medical appointments relating to your blood cancer or blood condition.

We hope that you find this diary useful and that it helps you feel informed.



#### **Important information**

It is important that you contact your doctor or the hospital for advice immediately (at any time of day or night) if you are feeling very unwell, or if you experience any of the following:

- A temperature of 38°C or above and/or an episode of shivering (rigors).
- Bleeding or unexplained bruising, for example blood in your urine, faeces, sputum, bleeding gums or a persistent nose bleed.
- Nausea or vomiting that prevents you from eating or drinking or taking your normal medications.
- Diarrhoea, stomach cramps or constipation.
- Shortness of breath.
- The presence of a new rash, reddening of the skin and/or itching.
- A persistent headache.
- A new pain or soreness anywhere.
- If you cut or otherwise injure yourself.
- If you notice pain, swelling, redness or pus anywhere on your body.

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## MY CONTACT AND PERSONAL INFORMATION

Name:		
Preferred name:		
Date of birth:	NHI number:	
	Postcode:	
Home phone:	Work phone:	
Mobile phone:	Email:	
My blood type:		
My allergies:		
MY EMERGENC	Y CONTACT	
Name:		
Relationship to me:		
Home phone:	Work phone:	
Mohile phone:	Fmail:	

If found, please contact Leukaemia & Blood Cancer New Zealand - 0800 15 10 15

#### **HEALTH CARE CONTACT DETAILS**

Name of general practitioner:	
Name of practice:	
Address:	
	Postcode:
Phone:	Email:
Name of Haematologist:	
Clinical nurse specialist:	
Treatment centre:	
Address:	
	Postcode:
Phone (clinical nurse specialist):	
Phone (outpatient/day stay):	
Phone (inpatient/ward):	
Phone (after hours):	
*In an emergency call 111 for an ambulanc	
Leukaemia & Blood Cancer New Zealand (	(LBC)
Support services coordinator:	
Phone 0800 15 10 15 extension:	
Mobile phone:	Email:

## OTHER IMPORTANT CONTACT DETAILS

e.g. social worker, pharmacist, physiotherapist, dietitian

Name	Role	Phone

## **MY MEDICATIONS**

Name	What is my medication for?

Dose	Further instructions

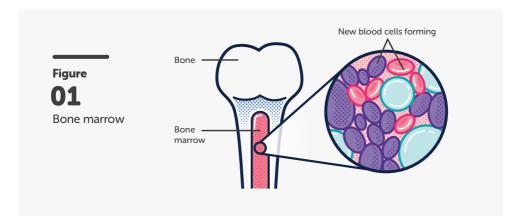
### **MY MEDICATIONS**

Name	What is my medication for?

Dose	Further Instructions

## BONE MARROW AND BLOOD STEM CELLS

If you have a blood cancer or condition it may be helpful to know about the cells in your bone marrow and blood.



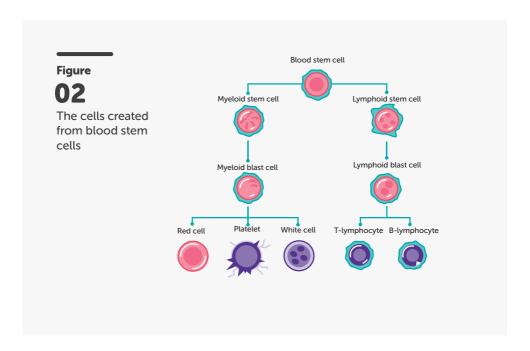
Bone marrow is the spongy material inside your bones (see Figure 01). In your bone marrow there are cells called blood stem cells. Blood stem cells create the new blood cells in your body.

The two main functions of blood stem cells are to:

- Make exact copies of themselves.
- Divide and make two different cell groups: myeloid (my-ill-oid) stem cells and lymphoid (lim-foid) stem cells.

Myeloid and lymphoid stem cells create the blood cells for your body including white blood cells, red blood cells and platelets.

In Figure 02 (on next page) you can see that the blood stem cell has divided to create a myeloid stem cell and a lymphoid stem cell.



#### **YOUR BLOOD**

The red blood cells, platelets and white blood cells, created in your bone marrow, are released into your bloodstream so they can function around the body.

Blood is made up of blood cells and plasma. A blood test measures the amount of each type of blood cell in your blood. The role of plasma and each type of blood cell is discussed below

#### Red blood cells

Red blood cells transport oxygen from the lungs to all cells in the body. A protein called haemoglobin (heem-a-glow-bin) in each red blood cell carries the oxygen throughout the body and also gives blood its red colour. A low level of haemoglobin in your body is called anaemia (a-nee-me-a).

#### White blood cells

White blood cells, also called leukocytes (loo-kar-sites), fight infection. For example, if bacteria entered your bloodstream through a cut, the white blood cells would attack and kill

the bacteria cells before they divide and spread. If your white blood cell count is low, you are more at risk of getting an infection.

Neutrophils (nutra-fils) are the most common type of white blood cell. A low amount of neutrophils in your body is called neutropenia (nutra-pee-nee-a).

#### **Platelets**

Platelets help your blood clot and prevent bleeding. For example, if you cut yourself, the platelets go to where the injury is, stick together and stop the bleeding. A low level of platelets in your body is called thrombocytopenia (throm-bo-sy-toe-pee-nee-a).

#### Plasma

Plasma is a light-yellow coloured liquid in which blood cells travel around your body.

#### **NORMAL BLOOD TEST RESULTS**

Table 01 gives you information about normal blood test results for adults. Table 02 gives you information about normal blood test results for children.

You may find this useful when you are having regular blood tests and want to compare your results with the normal range. Please note that there may be small variations compared with the data used at your hospital or clinic.

Table 01: Normal range for adults (local laboratory ranges may differ slightly)

	Adult men	Adult women
Haemoglobin (Hb)	130-175 (g/L)	115-155 (g/L)
Neutrophils	2.0-7.5 (x10 <sup>9</sup> /L)	2.0-7.5 (x10 <sup>9</sup> /L)
Platelets	150-400 (x10 <sup>9</sup> /L)	150-400 (x10 <sup>9</sup> /L)

Table 02: Normal range for children (local laboratory ranges may differ slightly)

	1-4 years	5-8 years	9-13 years	13-16 years (male)	13-16 years (female)
Haemoglobin (Hb)	105-140 (g/L)	113-145 (g/L)	115-145 (g/L)	126-160 (g/L)	115-150 (g/L)
Neutrophils	1.0-7.0 (x10 <sup>9</sup> /L)	1.5-8.0 (x10 <sup>9</sup> /L)	1.5-7.0 (x10 <sup>9</sup> /L)	1.8-7.0 (x10 <sup>9</sup> /L)	1.8-7.0 (x10 <sup>9</sup> /L)
Platelets	150-500 (x10 <sup>9</sup> /L)	150-475 (x10 <sup>9</sup> /L)	150-425 (x10 <sup>9</sup> /L)	150-400 (x10 <sup>9</sup> /L)	150-400 (x10 <sup>9</sup> /L)
White blood cells	5.0-14.5 (x10 <sup>9</sup> /L)	4.5-12.0 (x10 <sup>9</sup> /L)	4.3-12.0 (x10 <sup>9</sup> /L)	4.2-10.0 (x10 <sup>9</sup> /L)	12.0-15.0 (x10 <sup>9</sup> /L)

## WHAT HEALTH PROFESSIONALS WILL I MEET AFTER MY DIAGNOSIS?

Each health professional has a different area of expertise in cancer and cancer care. Working as a team, these health professionals will aim to give you and your family/ whānau the best available treatment and support so that you can live as well as possible.

Some of the health professionals you will meet are, in alphabetical order:

- Charge nurse A senior nurse in charge of an outpatient department, day unit or hospital ward.
- Clinical nurse specialist (CNS) A nurse
  with advanced skills in a specific area of
  clinical care. This person works closely
  with you and members of your health
  care team to coordinate treatment, and
  help you manage the symptoms of your
  condition and the side effects of treatment.
- Dietitian A dietitian may advise you on what to eat and drink to minimise symptoms or side effects from your condition or your treatment. They may also prescribe supplements to make sure you are getting the calories and nutrients you need.
- General practitioner (GP) A family and community doctor. They will work together with other health professionals to support you at home, in the community and after treatment. They can also refer you to a specialist if needed.
- Haematologist –A senior doctor who specialises in the treatment of blood cancers or blood conditions. A haematologist usually oversees any treatment for blood cancers and conditions.
- Occupational therapist Helps you manage everyday activities and achieve

activities you want or need to do.

- Outpatient clinic nurse A nurse who gives you treatment as an outpatient or who works alongside a doctor in clinic.
- Pathologist A doctor who specialises in the laboratory diagnosis of disease and how disease is affecting the organs of the body.
- Pharmacist Prepares and checks your drugs/medications. Pharmacists can advise you on how to take your medicine, possible side effects and interactions with other medications.
- Physiotherapist Specialises in maintaining and improving body movement and mobility.
- Psychologist Specialises in helping you manage the emotional challenges such as stress, anxiety and depression.
- Registrar A doctor who is in training.
   You may see a registrar in clinics, day units and wards. Registrars works closely with senior specialists (haematologists).
- Social worker Helps you manage the practical and emotional impact of the condition and its treatment, such as advice about managing at home, employment or school.
- Ward nurse A nurse who looks after you during a stay in hospital.

Other people you might hear about or meet are:

- Palliative care team Doctors, nurses and other health care professionals whose roles include managing symptoms, helping improve quality of life and supporting people at the end of life.
- Spiritual care and cultural support –
  People who can support your individual
  cultural, spiritual or religious needs.
- Non-governmental organisation (NGO) –
  Gives emotional and practical support for
  those affected by cancer, e.g. Leukaemia
  & Blood Cancer New Zealand (LBC).

LBC Support Services Coordinator –
 A professional who provides education as well as practical and emotional support.

 They can be contacted by calling 0800 15 10 15.

Meeting so many people can sometimes be confusing and overwhelming. It can be difficult to remember who does what job. If you are unsure, ask the person to remind you who they are and how they fit in to your health care team.

## QUESTIONS FOR MY HEALTH CARE TEAM

Communicating effectively with your health care team is important at all stages of your treatment and care. You can help to make the most of your appointments by being prepared, clear and concise through knowing what you want to learn from each meeting. You may wish to bring someone along with you to your appointments for support and to take notes.

The following are sample questions to ask your health care team:

- What is the name of my condition?
- Do I need further tests? What would these involve?
- What is the recommended treatment for my condition? Are there any alternatives to this treatment?
- When will treatment start and how long will it last?
- Where will I go for treatment?
- What are the common side effects of my treatment?
- How can I prepare myself for starting treatment?

- Will I need to take time off work/school or organise day care?
- If I can't work, am I eligible for financial assistance?
- Am I eligible for any clinical trials?
- Can I use complementary therapies? If so, which ones?
- Is there anything I shouldn't be eating/ drinking while on treatment?
- When is my next appointment? If my next appointment hasn't been confirmed, how will I find out about it (eg. via text, letter, phone call)?
- Do I need a prescription?

#### **MY APPOINTMENTS**

You may have appointments with a range of health professionals. Page 12 has a list of health professionals that you may meet following your diagnosis. Use the following pages to keep track of these appointments.

Date	Time	With	Location
e.g. 1/2/21	9.00am	Dr. Who	Outpatients

Reason
Routine Clinic

### **MY APPOINTMENTS**

Date	Time	With	Location
e.g. 1/2/21	9.00am	Dr. Who	Outpatients
		1	

Reason
Routine Clinic

Date:	Time:
My appointment is with:	
Points to discuss and questions to ask:	
Symptoms I have:	
Weight:	Blood Pressure:
Blood Test Results:	
Haemoglobin (Hb):	White blood cells (WBC):
Neutrophils (Neut):	Platelets (Plt):
Outcomes:	
My next appointment:	
Notes:	

Date:	Time:
My appointment is with:	
Points to discuss and questions to ask:	
— — — — — — — — — — — — — — — — — — —	
Symptoms I have:	
Weight:	Blood Pressure:
Blood Test Results:	
Haemoglobin (Hb):	White blood cells (WBC):
Neutrophils (Neut):	Platelets (Plt):
Outcomes:	
My next appointment:	
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Date:	_Time:
My appointment is with:	
Points to discuss and questions to ask	
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Symptoms I have:	
Weight:	Blood Pressure:
Blood Test Results:	
Haemoglobin (Hb):	White blood cells (WBC):
Neutrophils (Neut):	Platelets (Plt):
Outcomes:	
My next appointment:	

Date:	Time:
My appointment is with:	
Points to discuss and questions to ask:	
— — — — — — — — — — — — — — — — — — —	
Symptoms I have:	
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Neutrophils (Neut):	Platelets (Plt):	_
Outcomes:		
My next appointment:		
		_

Date:	Time:
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Weight:	Blood Pressure:
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Haemoglobin (Hb):	White blood cells (WBC):
Neutrophils (Neut):	Platelets (Plt):
Outcomes:	
My next appointment:	

Date	Hb	Plt	WBC	Neut

Date	Hb	Plt	WBC	Neut

Date	Hb	Plt	WBC	Neut

Date	Hb	Plt	WBC	Neut

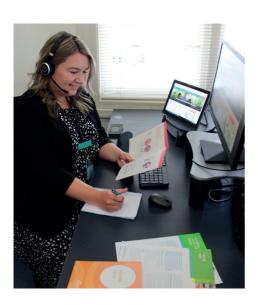
# LEUKAEMIA & BLOOD CANCER NEW ZEALAND

Leukaemia & Blood Cancer New Zealand (LBC) is the only organisation in New Zealand dedicated to supporting patients and their families/whānau living with a blood cancer such as leukaemia, lymphoma, myeloma, myeloproliferative neoplasms, myelodysplastic syndromes, and other serious blood conditions.

For over 40 years, our support has been made possible with funds received from key fundraising events such as Shave for a Cure, Trust applications and donations from individuals and organisations. We receive no direct government funding for the services we provide.

## **Patient Support**

Leukaemia & Blood Cancer New Zealand's Support Services provide personalised support programmes for patients and their



families/whānau. This can include regular visits, phone or email contact, as well as face to face education and support programmes, and an online information forum. We also provide a toll free number for advice and support which is 0800 15 10 15.

#### Research

Research plays a critical role in building a greater understanding of blood cancers and conditions. LBC support and fund investigation into these conditions. Improved treatments for patients can lead to less side effects and increased survival rates

#### Information

We provide vital information to patients, families/whānau, health professionals and the community to improve understanding about blood cancers and related conditions. You can find all our patient resources on our website at leukaemia.org.nz.

#### **Awareness**

We work to increase public knowledge of blood cancers and conditions. This is achieved through specifically focused campaigns for the public, health professionals and health agencies.

## Advocacy

We represent the needs of patients and their families/whānau to the government, related agencies and other relevant organisations.

# New Zealand Bone Marrow Donor Registry

Leukaemia & Blood Cancer New Zealand manages the New Zealand Bone Marrow Donor Registry (NZBMDR), which works towards finding matched volunteer donors from New Zealand or overseas for New Zealand patients who need a bone marrow or stem cell transplant and who do not have a family donor. The registry maintains information on New Zealand donors and has access to a worldwide database of over 20 million donors.

## Contacting us

Leukaemia & Blood Cancer New Zealand provide services and support throughout New Zealand. Each person's experience of living with a blood cancer or condition is different. Living with a blood cancer or a serious blood condition is not easy, but you do not have to do it alone.

Call 0800 15 10 15 to speak to a local Support Services Coordinator or to find out more about the services offered by Leukaemia & Blood Cancer New Zealand. Alternatively, contact us via email by sending a message to supportservices@leukaemia.org.nz or by visiting www.leukaemia.org.nz. We welcome visitors to our offices in Auckland, Hamilton, Wellington, Christchurch and Dunedin. Please phone for an appointment.



## **HAEMATOLOGY CENTRES IN NZ**

Centre	Address	Phone
Whangarei Hospital	Hospital Road, Whangarei	09 430 4100
North Shore Hospital	Shakespeare Road, Takapuna, Auckland	09 486 8900
Auckland City Hospital	Park Road, Grafton, Auckland	09 367 0000
Starship Hospital	Park Road, Grafton, Auckland	09 367 0000
Middlemore Hospital	Hospital Road, Otahuhu, Auckland	09 276 0044
Waikato Hospital	Pembroke Street, Hamilton	07 839 8899
Thames Hospital	Mackay Street, Thames	07 868 0040
Tauranga Hospital	Cameron Road, Tauranga	07 579 8000
Rotorua Hospital	Pukeroa Street, Rotorua	07 348 1199
Hastings Hospital	Omahu Road, Hastings	06 878 8109
Whakatane Hospital	Stewart Street, Whakatane	07 306 0999
Palmerston North Hospital	Ruahine Street, Palmerston North	06 356 9169
Wellington Hospital	Riddiford Street, Newtown, Wellington	04 385 5999
Nelson Hospital	Tipahi Street, Nelson	03 546 1800
Christchurch Hospital	Riccarton Avenue, Christchurch	03 364 0640
Dunedin Hospital	Great King Street, Dunedin	03 474 0999
Invercargill Hospital	Kew Road, Invercargill	03 218 1949

## **QUESTIONS & NOTES**

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### **Contacting us**

Leukaemia & Blood Cancer New Zealand provides services and support throughout New Zealand. Every person's experience of living with a blood cancer or condition is different. Living with leukaemia, lymphoma, myeloma or a related blood condition is not easy, and our Support Services Coordinators are here to help.

Freephone 0800 15 10 15 Telephone 09 638 3556 Email info@leukaemia.org.nz

#### **National Office**

6 Claude Road, Epsom 1023 PO Box 99182, Newmarket 1149 Auckland, New Zealand

## leukaemia.org.nz

OD - 9148 - 2018 Charities Commission no. CC34498



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